#RARE DISEASE DAY

MORE THAN YOU CAN IMAGINE

FEB 28 2025

**Maria Nassif from France,
living with Homozygous Familial
Hypercholesterolaemia (HoFH).**

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My name is Maria and I am a patient with Homozygous familial hypercholesterolemia (HoFH), diagnosed at the age of three. My understanding of my disease deepened in my early teens when I started to do my own research. I have found out that it is a rare genetic and chronic disease characterised by having a high level of cholesterol in the blood from birth and that I'll be living with this condition for the rest of my life.

People I encounter every day express disbelief when they know about my disease especially when they estimate I have a slender body shape. So I end up presenting the cool science behind it, listing all the medicines that I take and explaining how the three hours of LDL apheresis is done.

My past athletic life and vibrant lifestyle perplexes them even more, especially when they find out I underwent open-heart surgery at the early age of 24 years old. They go through a roller coaster of emotions seeing how I carry on well with my life.

It is a roller coaster for me as well, on both emotional and mental levels. One day I feel fine, but the very next I wake up tired, fearing that I will have

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a heart attack knowing that I have cardiovascular diseases which allows anxiety to set in my head and ruin my day until I feel well again.

Additionally, living with HoFH requires thorough scheduling between treatments, echoes, tests, and consultation appointments. On one hand, my work and on the other, my life's agenda which is pretty challenging especially when it comes to managing my projects. Being a rare disease, very few people know about HoFH and the struggles we face daily, that we often feel like strangers within our society.

Moreover, very few countries offer good practices to their patients and the others do not at all.

That's why I have joined FH EUROPE FOUNDATION where I have found my community and together, as patient ambassadors, we raise awareness about familial hyperlipidaemias and help other patients like us have access to an efficient and personalised treatment.

In conclusion, having HoFH, is more than you can imagine.

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